DESIGN OF A HEALTH INDICATOR SYSTEM:

A "HOW-TO" MANUAL FOR STATE MEDICAID PROGRAMS

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FORWARD

Is our public investment in providing health coverage through Medicaid improving the health outcomes of the population served by the program? How do the health outcomes of this population compare to other groups of citizens? It is critical for state and federal policy makers to be able to answer these questions.

Design of a Health Indicator System: A How-To Manual for State Medicaid Programs shows states how to answer this question by setting up an evaluation infrastructure within their Medicaid program. The manual explains the step-by-step process Rhode Island uses to evaluate health outcomes in its Medicaid program: selecting population-specific health outcome measures, gathering and analyzing data. This information can then be used to create baseline measures of health status, design new program initiatives, and evaluate program impact on health outcomes of Medicaid enrollees.

We are grateful to the Center for Health Care Strategies for providing Rhode Island with the opportunity to expand our capacity to trend health outcomes for our entire Medicaid population, and to share this design with other states.

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I. EXECUTIVE SUMMARY

Background: The Conceptual Framework of the Health Indicator System

The purpose of the health indicator system is to provide information based on State and national level data for the development, monitoring and evaluation of programs that serve populations on Medicaid. This project was developed initially for Rhode Islanders on Medicaid by the Division's Evaluation Studies Workgroup (see list of workgroup members in Appendix 1).

The workgroup selected a classification system that would allow for categorization of health indicators along two dimensions. The first dimension is the three basic evaluation components of the health care system: **structure, process and outcome**. The second dimension is the three basic components of health care: **preventive, acute and chronic**. The Medicaid population was divided into four age based core matrices representing health care needs and program responsibilities. The age categories are infants and children (birth - age 11); adolescents (ages 12-20); working aged adults (ages 21-64); and elderly adults (ages 65+).

The Evaluation Studies Workgroup, for this planning project, designed the initial set of two core age-based health indicator matrices for healthy adolescents (see Appendix 2) and for healthy adults (see Appendix 3) and two indicator modules for adults with disabilities (see Appendix 5) and for children with disabilities (see Appendix 4). These two subgroups were selected because the Medicaid program is planning program interventions to address the needs of these populations. However, this system is highly flexible. It has the capacity to develop new modules as new needs arise. If, for example, a state were to design a specific

program intervention for children with asthma or adults with traumatic brain injury, a module tailored to monitoring the success of specific program features and health care goals could easily be constructed.

Methods: Selecting Health Indicators and Setting-Up a Medicaid Data Archive

Design of the health indicator system in Rhode Island was a three-step process. First health indicators matrices were developed, indicators were selected from existing literature and then data sets were acquired that measured the selected indicators. These selected data sets created the Medicaid Data Archive. **Health indicators were selected by reviewing existing research literature, policy reports and performance measure projects**. A health indicator was selected if it was recommended by two or more studies.

After the health indicators were selected, data sets were identified that collect the indicators and data gaps noted. **Health indicators were then reviewed by Medicaid program staff so they could choose the indicators that were most useful to monitor and evaluate their new program initiatives**.

In order to assess, design, monitor and evaluate health services and program interventions for populations on Medicaid, reliable data sets that contain these health indicators need to be available on-site for the Medicaid program. As part of this planning grant a Medicaid Data Archive was established to ensure that data sets were documented and accessible for program and policy staff. Eleven data sets were reviewed and eight data sets were selected based on their reliability, accuracy and ability to track indicators over time. **Data sets in the Medicaid Data Archive include public health data sets, available in most states, including Hospital Discharge, Vital Statistics - Birth File, Minimum Data Set for Nursing Home Residents, and the Behavioral Risk Factor Surveillance System.**

Results: Creation of Health Indicator Matrices for Children and Adults with Disabilities and Production of Health Indicators from Medicaid Data Archive

Once a Medicaid Data Archive has been established it can be used by program staff to design new program initiatives, create baseline measures of unmet need, and trend health outcomes of Medicaid beneficiaries compared to populations on private insurance. In Rhode Island seven of the data sets selected have been loaded on the archive personal computer (see Appendix 7 for description of each data set). Documentation is complete on five of the eight data sets (i.e, codebooks completed and frequencies verified).

As part of this planning grant, health indicators were selected from the policy and research literature for adults and children with disabilities. Indicators that were the same for children and adults included access to specialists, mental health visits, hospital re-admissions, information on disability, emergency department visits , respite care, social functioning, functional status and satisfaction. The next step in the implementation phase of this project is to use the Medicaid Data Archive to create reliable baseline measures for children and adults with disabilities on Medicaid.

Rhode Island has developed a set of questions for selection of a health indicator for use by other states and plans to assess their answers in relation to the health indicators designed for populations with disabilities. The questions States need to pose when selecting a health indicator include:

- Does the indicator measure a standard or goal that should be achieved and maintained?
- Is there evidence that the indicator provides meaningful information about selected health topic?
- Is there a consistent way of measuring the health indicator over time so that the indicator is reliable and trends can be monitored?
- Are there guidelines, benchmarks, performance measures or objectives set by professional organizations to use as standards?
- Is the indicator sensitive to change and can it measure effectiveness of health service programs?
- Is indicator similar to those used in other geographic areas so state and national comparisons can be made?

Two examples of health indicators are interpreted and displayed that meet the above guidelines. The two indicators selected as examples of how to produce a health indicator are - access to health care and asthma hospitalization. These two indicators are readily available in all states.

II. BACKGROUND

A. Purpose of Health Indicator System

The purpose of the health indicator system is to provide information based on state and national level data for the development, monitoring and evaluation of programs that serve populations on Medicaid. The Evaluation Studies Workgroup in Rhode Island has designed a conceptual framework and structure for an indicator system that has broad as well as targeted applicability (see Appendix 1 for workgroup members). The methodology of and criteria for indicator selection were modeled after those used in the selection of criteria for the RIte Care program, Rhode Island's Medicaid managed care program for families.

B. Conceptual Framework

The Evaluation Studies Workgroup reviewed reports of similar efforts to identify a framework that would be responsive to program and population monitoring needs. The workgroup selected a classification system that would allow for categorizing indicators along two dimensions. The first dimension is the three basic evaluation components of the health services system: ***structure, process, and outcome.*** The second dimension is the three basic components of health care: ***preventive, acute, and chronic.***

Creating indicators for program or system structure, process of care, and patient outcome will allow for monitoring system goals such as increasing the number of specialists participating as providers in the Medicaid program; for monitoring improvement in the delivery of care such as immunizing children according to recommended guidelines; and for monitoring patient outcome such as reduction in hospitalization for ambulatory care-sensitive conditions.

Indicators can also be categorized according to the focus of care, namely, preventive care, acute care, and chronic care. Given the importance of all aspects of care in meeting the needs of both well and chronically ill people in the Medicaid population, this classification scheme ensures adequate representation of indicators to match the full spectrum of program objectives.

C. Indicator System Structure

Perhaps the greatest challenge in designing an indicator system for the Medicaid population is the heterogeneity of its members. While some health care goals are common to all, many goals are particular to an individual's age, institutional versus community residence, healthy versus special needs health status and, among the disabled, physical versus cognitive disability. This challenge is complicated by the needs of program administrators to monitor subgroups of beneficiaries according to program membership (e.g., home and community based waiver beneficiaries), residential status (nursing home residents or state hospital patients, for example), age, and other relevant factors. With the increasing importance of medical condition management, monitoring people with a specific diagnosis (in response to a diabetes management program, for example) is important. Care objectives, and consequently, indicators by which to measure status and progress toward objectives, can vary considerably.

In response to this considerable challenge, the Evaluation Studies Workgroup has devised a ***modular structure*** for indicator monitoring system. Indicators are categorized in matrices, with the two organizing schema described (*structure, process, outcome* and *preventive care, acute care, chronic care*) forming the axis of each matrix.

Given the primary relation of age to both the nature of health problems and the goals of health care delivery, the health indicator system has ***age-based core matrices of indicators*** relevant to all beneficiaries regardless of variation in other factors such as disability or residential status. The Medicaid population is divided by age into four core matrices:

- Infants and Children (birth to age 11)
- Adolescents (ages 12-20)
- Adults (ages 21-64)
- Elderly Adults (ages 65+)

The majority of indicators in these core matrices focus on preventive care (e.g., immunization, primary care utilization, and health screening). Health indicators for different age categories of program interest can be developed as modules (e.g., older elderly 85+, adolescent and young adults in transition 18-21, and preschool <5). Figure 1 and 2 are the core indicators developed for adolescents and adults. (Note: Indicator selection process is discussed in section III). Health indicator modules can be added to the core matrices. These health indicators are specific to the special needs of population subgroups and program objectives. Modules can be developed for all age groups to monitor individuals with chronic illnesses and disabilities. For example, preventive care for groups with special needs will include indicators designed to monitor secondary prevention efforts such as the maintenance of health status and avoidance of comorbidities. These modules will include mostly chronic

care indicators, both medical (e.g., myocardial infarctions) and social in nature (e.g., work status for the adults with disabilities).

Other modules based on factors that warrant separate monitoring can be designed; for example, separate modules are required for the elderly population who live in nursing homes and those who reside in the community. Modules can be tailored for adults with mental illness, with developmental disabilities, or with physical disabilities. Figure 3 shows the module developed for elderly nursing home residents.

The Evaluation Studies Workgroup for this project designed an initial set of two core age-based indicator matrices (i.e., teenagers and adults) and two indicator modules addressing health care needs of adults with disabilities and children with disabilities. These two subgroups were selected because the Rhode Island Medicaid program is designing new intervention programs which address the needs of these two groups. However, this system is highly flexible. It has the capacity to develop new modules as new needs arise. If, for example, a state designs a specific program intervention for children with asthma, or adults with traumatic brain injury, a module tailored to monitoring the specific program features and health care goals of these programs is a simple modification of the basic matrix design.

FIGURE 1
CORE HEALTH INDICATORS* FOR HEALTHY ADOLESCENTS - AGES 12-20

	Structure	**Process**	**Outcome**
Preventive	Primary care providers (e.g. school-based clinics, pediatricians, nurse practitioners)	History & Physical exams Dental visits Family planning visits Immunization Screening for: Depression AIDS/HIV Asthma	Weight Sexual activity Tobacco use Alcohol use Drug use School drop-out Violence/Injury
Acute			Mental health readmits STD rates Pregnancy rate
Chronic	Specialists		

*Indicators selected by literature review and existing performance measure projects.

See Appendix 2 for references.

FIGURE 2
CORE HEALTH INDICATORS* FOR HEALTHY ADULTS - AGES 21-64

	Structure	**Process**	**Outcome**
Preventive	Primary care providers	History & Physical exams Dental Services Prenatal Care Immunization Screening: depression cholesterol mammogram pap smear colorectal diabetic retinal exam HIV/AIDS Asthma	Tobacco use Alcohol use Drug use Violence/Injury Functional status
Acute			Mental health readmits Hospitalizations for ambulatory care sensitive conditions (acs)
Chronic	Specialists		

* Indicators selected by literature review and existing performance measure projects.
See Appendix 3 for references.

FIGURE 3
HEALTH INDICATOR* MODULE FOR NURSING HOME ELDERLY

	Structure	**Process**	**Outcome**
Preventive	Exercise classes available	Physical Therapy Use of restraints Use of catheters Flu vaccine Pneumonia vaccine	Primary care visits Dental visits Falls UTIs
Acute			Hospitalizations for ambulatory care sensitive conditions Readmits for same diagnosis Hospital days
Chronic	Geriatricians Other specialists	Protocols for: pain management skin maintenance Depression screens	Pain Pressure ulcers Functional decline Untreated Depression Drug reactions

* Indicators selected by literature review

This flexibility of module development expands the usefulness of this system beyond the needs of state Medicaid program directors to other state agencies who are responsible for the care of these populations, (e.g., Department of Elderly Affairs, Department of Mental Health Retardation and Hospitals, Department of Health, Department of Children, Youth and Families, Department of Education and other community agencies). Projects need to solicit input from other state agencies and community groups as part of the indicator selection process.

III. METHODOLOGY FOR HEALTH INDICATOR SYSTEM

A. Selection of Health Indicators

1. Review of policy studies, quality assurance projects, *and the research literature*

The wisdom of using empirical indicators to target areas for intervention and to monitor organizational and program performance, as well as evaluate patient outcome has been recognized nationally and internationally. **Health indicators were selected by reviewing existing literature, policy reports and performance measure projects**. A health indicator was selected if it was recommended by two or more of the studies reviewed.

For this planning project, studies were reviewed and health indicators were selected for four population groups.

- Healthy Adolescents (see Appendix 2)
- Healthy Adults (see Appendix 3)
- Children with Disabilities (see Appendix 4)
- Adults with Disabilities (see Appendix 5)

This method of creating a matrix to select measures illustrates the extent of consensus on an indicator of health care quality. For example ten of the eleven studies reviewed for healthy adolescents recommended drug use as a health indicator, whereas only two of the eleven recommended sexual activity.

Eleven studies that focused on adolescent health needs and performance measures were reviewed for the Healthy Adolescent Matrix (see results in Appendix 2). Twenty health indicators were selected that focused on primary care/prevention, risk taking behavior and chronic disease follow-up.

In the matrix for healthy adults, eight policy and performance measure projects were reviewed (see results in Appendix 3). From this review seventeen health indicators were selected which included preventive screening, substance abuse, ambulatory case sensitive hospitalizations and other chronic disease follow-up.

For populations with disabilities, reports and literature were reviewed if they had a recommended list of quality and performance measures for children or adults with disabilities. For children with disabilities eight reports were reviewed and 40 indicators selected (see results in Appendix 4). For adults with disabilities ten reports were reviewed and 33 indicators selected (see results in Appendix 5). The indicators for populations with disabilities were divided into structure, process and outcome categories.

The consensus list of indicators for populations with disabilities was much greater than for healthy populations due to the greater health care needs of these populations. Also, indicators for healthy populations clustered more within the preventive category, whereas indicators for populations with disabilities clustered more in the chronic category. Measures selected included linkages across agencies and providers, hospital re-admissions, preventive care, family support, functional status, work or school missed, satisfaction with care, and access to respite or specialty care.

2. Identification of potential data sources

Available state and program level data sources were reviewed for their usefulness to the project (e.g., Medicaid eligibility and claims data bases, statewide surveys and population databases such as hospital discharge and birth files). While some data sources are useful for monitoring the Medicaid population only, e.g., Medicaid claims data, other sources also allow for comparisons of the Medicaid population to the Rhode Island general population, e.g., hospital discharge data and the Behavioral Risk Factor Surveillance System (BRFFS). Potential data sources were evaluated for:

- generalizability to their target position
- reliability and accuracy
- accessibility
- availability over time to monitor trends
- availability of national data sets for comparison

Data sets identified to be "core" to this effort will be acquired and maintained by the Medicaid Health Data Archive located on site in the Division of Health Care Quality, Financing and Purchasing (see figure 5 p.19 for data sets in archive).

3. *Identification of data gaps*

When there is not an existing database to measure selected health indicators, the Evaluation Studies Workgroup recommended special surveys or new data collection systems (e.g., patient intake or needs assessment surveys) to obtain these measures. There are a

variety of subjective indicators that can only be collected by targeted surveys or regular assessments of specific populations of interest, such as satisfaction with or barriers to medical care, perceptions of unmet need for services, or functional status. Figure 2 in each of the four indicator matrices in Appendices 2 - 5 show the results of data set availability by each health indicator.

4. Medicaid Program Staff - Input

After the matrices were developed meetings were held with Medicaid program staff to determine their priorities for health indicator selection. Following is a list of criteria program staff can consider in selection of health indicators.

- There is expert consensus, or in the absence of consensus, empirical evidence of the validity of the measure's value as a quality indicator
- Measure is indicative of a standard that should be achieved or maintained (e.g., high rates of annual pap smears among adult women)
- Measure is an outcome where improvement is needed (e.g., high rates of sentinel events such as avoidable hospitalizations)
- Measures achievement of a specific program goal or program priority (e.g., increase in system capacity or increase in access to health insurance).
- Measure is sensitive to change as a result of a proposed or ongoing program.
- Measure is found on national and state data sets so comparisons can be made.
- Measure is reliable so trends can be tracked over time.

Rhode Island Medicaid staff selected health indicators to monitor or evaluate new program initiatives. Their priorities for health indicators are marked with a asterisks on Figures 1 and 2 of each matrix in Appendices 2 - 5.

5. *Stakeholder Input*

Health Indicator Systems need review by stakeholder groups. It is important to ensure that the project meets the needs of other providers and consumers. To date the Evaluation Studies Workgroup has presented this planning project to one group of state agency stakeholders (see Appendix 6 for participants). This group was supportive of the indicator system and appreciated its flexibility to measure different age groups and sub-populations. There was enthusiastic interest in using the health indicator system to develop and evaluate new program initiatives. The group will to continue to meet to discuss data needs, baseline measures, and needs assessment results.

B. Set - Up Medicaid Data Archive

The major purpose of the Health Indicator System is to assess, design, monitor and evaluate health services and program interventions for populations on Medicaid. In order to fulfill this purpose reliable data sets that contain these health indicators need to be available and accessible on-site for the Medicaid program. Rhode Island, as part of this planning grant, has established a Medicaid Data Archive to meet this goal for its Medicaid program. The archive consists of reliable and well documented public health data sets, special surveys and Medicaid program data. **This section explains the steps necessary for a state to set-up a Medicaid Data Archive.**

1. *Selection Criteria for Data Sets*

Data sets were reviewed for selection if they collected health indicator measures on Rhode Islanders. Eleven Rhode Island data sets were identified as potentially useful to the project (see Figure 4). Three additional criteria were required for inclusion in the archive:

- Either a statewide population based data set that includes health indicators and measures insurance status OR a data set collected on all Medicaid recipients that includes health indicators.
- Reliable and accurate data set with documentation
- Ongoing data collection so annual trends can be monitored or pre-post test measures can be compared

Figure 4 shows the results of this selection process. Of the eleven data sets reviewed, eight were selected for inclusion in the Medicaid Data Archive.

FIGURE 4
RHODE ISLAND DATA SETS REVIEWED BY SELECTION CRITERIA

DATA SETS	SELECTION CRITERIA			
	Statewide population based data set that measures insurance status	**OR** Data set that measures health indicators for Medicaid recipients	Reliable and accurate data set with documentation	Ongoing data collection for annual trends **OR** pre/post test results
1. Hospital Discharge *	X		X	X
2. Vital Statistics Death File			X	X
3. Vital Statistics Birth File *	X		X	X
4. Minimum Data Set for Nursing Home Residents *	X		X	X
5. Behavioral Risk Factor Surveillance System *	X		X	X
6. RI Health Interview Survey *	X		X	X
7. Cancer Registry			X	X
8. Infant Health Survey *	X		X	X
9. Children with Disabilities Survey *		X	X	X
10. Medicaid Management Information System (MMIS) *		X	X	X
11. Youth Risk Factor Surveillance System				X

*= Data Set meets all three selection criteria

2. *Checklist for Data Set Documentation and Dissemination*

A data archive is not merely a warehouse that stores data, but functions as alibrary that documents the data set and makes it accessible and available for Medicaid program staff, researchers and other state agencies. In order for an archive to function resources need to be allocated for data acquisition, documentation and ongoing dissemination. Following are the steps necessary to establish and maintain a data archive:

- Collect data collection form or original survey - It is important to have the original data collection form or survey so users of the archive can see how a question was asked and coded to assist in formulating their own questions and hypotheses.

- Create SAS data set from raw data file - A single analytic software should be selected for analysis of all data sets. Statistical Analysis Software (SAS) was selected as the software for analysis in the archive.

- Create data dictionary for each data set in the archive - The dictionary includes a data set description, codebook with variable descriptions and values, frequency runs on all variables and selected crosstabs. This documentation is critical for program or resource staff who want to become familiar with the contents of the data set.

- Run and review frequencies for accuracy - The majority of the data sets in the data archive are public health data sets overseen by the Department of Health. These data sets are collected and updated on a yearly basis. It is important to ensure that archive data is reliable and matches the original source data. This usually involves several meetings and data checks to ensure that data is consistent from year to year.

- Implement and Conduct data requests - Once the data set is documented and verified users can start to make data requests. The data archive needs to establish a data request policy. The archive needs an analyst who can explain how the data set can answer policy questions.

- Disseminate findings - The major purpose of the Medicaid Data archive is to monitor selected health indicators for Rhode Islanders on Medicaid both by comparison to the privately insured and by tracking trends overtime. Findings will be disseminated through reports and studies.

3. Recommendations for hardware and software

The Rhode Island Medicaid Data Archive has the following computer capabilities:

- Pentium III 500 Mhz Processor
- 256 MB SDRAM
- 19 GB hard drive
- 44x CD - ROM
- Windows 98
- SAS System for Windows - Base & Stat
- Graphic and spreadsheet software - Excel, Harvard Graphics, Power Point

Rhode Island has selected a PC environment to operate the archive, which has made both transfer across data platforms and access to data easier for other end users. When choosing a PC system, it is best to purchase the fastest processor available (i.e., 500 Mhz) and highest megabyte (MB) of ram (i.e., 256) so data analysis is rapid. It is best to purchase the largest hard drive for storage of data sets.

IV. RESULTS

A. Rhode Island Medicaid Data Archive - Description and Content of Data Sets Collected

Eight of the eleven data sets reviewed for the Medicaid Data Archive met the selection criteria. Figure 5 shows the description and content of the eight data sets. The table describes the sample, shows geographic comparison, demographic and health outcome measures available for each data set.

Five of the data sets are existing public health data sets; two are special surveys

and one is a program data set. Appendix 7 contains a one page summary for each of the eight data sets describing the purpose, methods, years available and selected health indicators. Data sets included in the Medicaid Data Archive by type are:

Public Health Data Sets

1. Hospital Discharge
2. Vital Statistics - Birth File
3. Minimum Data Set - Nursing Home
4. Behavioral Risk Factor Surveillance System
5. Rhode Island Health Interview Survey

Special Surveys

6. Infant Health Survey
7. Rhode Island Children with Disability Survey

Program Data Sets

8. Medicaid Management Information System

FIGURE 5 - RI MEDICAID DATA ARCHIVE - Description and Content of Data Sets Selected

Data Set/Survey & Available Years	Description of Sample	Geographic Comparison			Demographic Measures								Health Outcome Measures						
		NATION	STATE	LOCAL	AGE	SEX	RACE	CENSUS	EDUC	INCOME	INSUR	SITE	ICD9	MEDCON	LOS	UTILIZ	MEDREC	DISAB	COST
1. Hospital Discharge – Ambulatory Care Sensitive Condition FY1992-1997	RI hospital discharges for ambulatory care sensitive (acs) conditions for all ages- annual acs discharges = 20,000	x	x	x	x	x	x	x			x	x	x		x	x			x
2. Vital Statistics - Birth File CY1993-1998	All RI births - annual births =12,500	x	x	x	x	x	x	x	x		x	x		x	x	x			
3. Minimum Data Set Nursing Home Residents 1998 (MDS)	All RI nursing home residents - annual residents = 10,000	x	x	x	x	x	x		x		x	x	x	x	x			x	
4. Behavioral Risk Factor 1996-98 Surveillance System (BRFSS)	Representative sample of Rhode Islanders > age 18 (n =1,800-3,600)	x	x		x	x	x		x	x	x			x		x		x	
5. RI Health Interview Survey 1990 & 1996	Representative sample of all Rhode Islanders (n=6,500)		x	x	x	x	x	x	x	x	x	x		x		x		x	
6. Infant Health Survey 1993 &1995	Birth cohort of Providence Inner City one year old infants (n=678)		x	x	x	x	x	x	x		x	x	x	x	x	x	x	x	
7. Children with Disabilities Survey 1997	Random sample of RI children ages 1-21 on fee-for-service Medicaid (n=257)		x	x	x	x	x	x			x	x	x	x	x	x		x	x
8. Medicaid Management Information System (MMIS) CY1998	Eligibility and Claims data on RI adults and elderly on Medicaid fee-for-service (n=42,000)	x	x	x	x	x	x	x			x	x	x	x	x	x		x	x

B. Rhode Island Medicaid Data Archive - Progress Report on Data Acquisition and Documentation

It is important to document progress to keep track of the status of each data set. Figure 6 shows the progress made in acquiring, documenting and analyzing the eight data sets in the Medicaid Data Archive. Seven of the eight data sets are loaded on the archive personal computer. Documentation is complete on five of the eight data sets (i.e., codebooks have been developed and frequency runs have been verified).

Medicaid program staff have begun to use the data archive. Requests have been implemented through analysis of the birth file, hospital discharge and Behavioral Risk Factor Surveillance System (BRFSS). Baseline and trend maternal and child health indicators have been reported from the birth file by insurance (e.g., adequacy of prenatal care, interbirth interval, maternal smoking and low birthweight) and hospital discharge (e.g., rates of ambulatory care sensitive conditions by age).

The BRFSS has been used to create population estimates of employed and unemployed persons-in-need of health insurance for a statewide program. Baseline unmet need measures are also available for children with disabilities on Medicaid.

FIGURE 6 - RHODE ISLAND MEDICAID DATA ARCHIVE
Progress Report on Data Acquisition and Documentation

DATA SETS	Birth File	Infant Health Survey	Children w/ Disability Survey	Hospital Discharge	BRFSS	Health Interview Survey	MMIS	MDS
DATA ACQUISITION								
Select/Design Data Set	X	X	X	X	X	X	X	X
Obtain/Collect Data	X	X	X	X	X	X	X	1
Create SAS Data Extract Files	X	X	X	X	X	X	1	
DOCUMENTATION OF DATA SET								
Collect Data Collection Forms/Questionnaires	X	X	X	X	X	X	X	X
Create Code Book Including Record Layout and Variable Descriptions with Values	X	X	X	X	X	1	1	
Code to Run Frequencies	X	X	X	X	X	1	X	
Run Frequencies	X	X	X	X	X	1	1	
Review/Verify Frequencies	X	X	X	X	X	1	1	
ANALYSIS OF HEALTH INDICATORS								
Design Indicators	X	X	X	X	1			
Code to Calculate Indicators	X	X	X	X				
Calculate Baseline Indicators	X	X	X	X				
Review Baseline Indicators	X	X	X	1				
Report Baseline Indicators	X	X	X					
Calculate Trend Analysis	X	X						
Review Trend Analysis	X	X						

Status: X = Completed, 1 = In Progress

C. Health Indicators for Children with Disabilities

Figure 7 shows the results of health indicator selection for children with disabilities. The health indicators selected by policy reports and literature review in Appendix 4 were placed in the preventive, acute, and chronic categories. The figure also notes the priority indicators selected by Medicaid program staff. Staff selected fourteen priority indicators out of the 40 selected through the policy and research literature review.

The next steps in the implementation phase of this project are to assess availability of these indicators on existing data sets; determine gaps where data set development is needed; and create reliable baseline measures from data sets in the Medicaid Data Archive.

In addition the Rhode Island Medicaid program also plans to use these indicators to help design an intake and follow-up assessment form for their new initiative for children and adolescents with disabilities (i.e., CEDARR Family Center of Care).

FIGURE 7
HEALTH INDICATORS MODULE FOR CHILDREN WITH DISABILITIES

	Structure	Process	Outcome
Preventive	Pediatrician Knowledge of Disability Support Services * (transportation, home care, respite) Parents on Advisory Group	Preventive Visits Dental Visits Mental Health Visits * Up-to-date Immunizations Up-to-date on Screening (lead, anemia) Length of Time w/ PCP Family receives Information on Disability	Emotional functioning * Social functioning *
Acute	Access weekends & nights*	Acute Visits Emergency Department Visits *	Hospital readmits * (ACS conditions) School Performance School Days Missed * Bed Days Satisfaction
Chronic	Access to Facility Pediatric Specialists * Written Agency Linkages in Place Quality of Care Protocols in Place Grievance and Appeals Process in Place	Screen for Disability Pharmacy Specialty Care * Durable Medical Equipment* Respite Care * MD and other providers coordinate care plan w/ school * PCP and Specialist Coordinate Care	Functional Status * Global Health Status Total $ spent on child

Note: Policy and research references for each indicator listed in Appendix 4
* Medicaid Program Staff Priorities

D. Health Indicators for Adults with Disabilities

Figure 8 shows results of health indicator selection for adults with disabilities. The health indicators selected by policy reports and literature review in Appendix 5 were placed in the preventive, acute, and chronic categories. The figure also notes the priority indicators selected by the Medicaid program staff. Staff selected six priority indicators from the 33 selected from the policy and research literature.

The next steps, in the implementation phase of this project, are to assess availability of these indicators in existing data sets; determine gaps where data set development is needed; and create reliable baseline measures from data sets in the Medicaid Data Archive. In addition, the Rhode Island Medicaid Program plans to use their indicators to help design an intake and follow-up assessment form for its new Disease Management Program for adults on fee-for-service Medicaid.

FIGURE 8

HEALTH INDICATOR MODULE FOR ADULTS WITH DISABILITIES

	Structure	Process	Outcome
Preventive	Assisted Living Facilities Community Based Services	Outpatient mental health Depression Screen Substance Abuse Screen	Unmet need for care Pain/symptoms * Patient knowledge of condition Social functioning Ambulatory Care Sensitive Hospitalizations *
Acute		Hospital Stays & Days Emergency Department Visits Skilled Home Health (RN)	Hospital Readmission (mental, ACS) * Satisfaction *
Chronic	Specialists Adult Foster Care Facilities Existing Organizational Linkages Availability of Durable Medical Equipment	Nursing Home Stays & Days Unskilled Home Health Rehabilitative Services (PT, OT, ST) Adult Daycare Respite Care Chronic Follow-up Care (e.g. AIDS, depression, diabetes, asthma)	Functional Status * Depression * Patient involvement in care

Note: Policy and research references for each indicator listed in Appendix 5.
* Medicaid Program Staff Priorities

E. Examples of How to Produce a Health Indicator from the Medicaid Data Archive

The health indicators selected for this planning report can be used to target areas for intervention, monitor health status, and evaluate patient outcome and program performance. The challenge is to develop health indicators that are meaningful and useful. The following list of questions can assist states in designing health indicators that embody the selection criteria in the Methods section.

- An agreed upon priority - Does the indicator measure a standard or goal that should be achieved or maintained? Does the indicator have relevance for public or programmatic decisions?

- Validity - Is there evidence that the indicator provides meaningful information about the selected health topic? Does a change in the indicator reflect a change in the health issue?

- Reliability - Is there a consistent way of measuring the health indicator over time so that the indicator is reliable and trends can be monitored? Is there support for the continued measurement of the indicator?

- Current standards in use - Are there guidelines, benchmarks, performance measures or objectives set by professional organizations to use as standards? (e.g., Healthy People 2010 Objectives, clinical standards, HEDIS, FACCT)

- Useful for program evaluation - Is the indicator sensitive to change and can it measure effectiveness of health service programs? Will activities directed toward reducing a health problem be reflected in a change in the indicator?

- Comparability - Is the indicator similar to those used in other geographic areas so more state and national comparisons can be made?

The following section shows how to interpret and display, using tables and graphics, two examples of health indicators that meet the above criteria. The two indicators selected as examples are:

- ***Access to Health Care***

- ***Asthma Hospitalization***

1. *Access to Health Care*

Access to health care is a national policy concern. In the Behavioral Risk Factor Surveillance Survey (BRFSS), respondents are asked a number of questions concerning their use of health services as well as the barriers to health services they experience. In the years 1996 through 1998, respondents in the BRFSS were asked:

> *Was there a time during the past 12 months when you needed to see a doctor but could not because of cost?*

In Rhode Island during the years 1996 through 1998, 8.19% of persons were not able to see a doctor because of cost issues. However, as Table 1 indicates, the response to this BRFSS question varies by respondent's insurance status. More than three times as many uninsured Rhode Islanders than Medicaid enrolled Rhode Islanders responded that they could not see a doctor in the past year because of cost.

Table 1

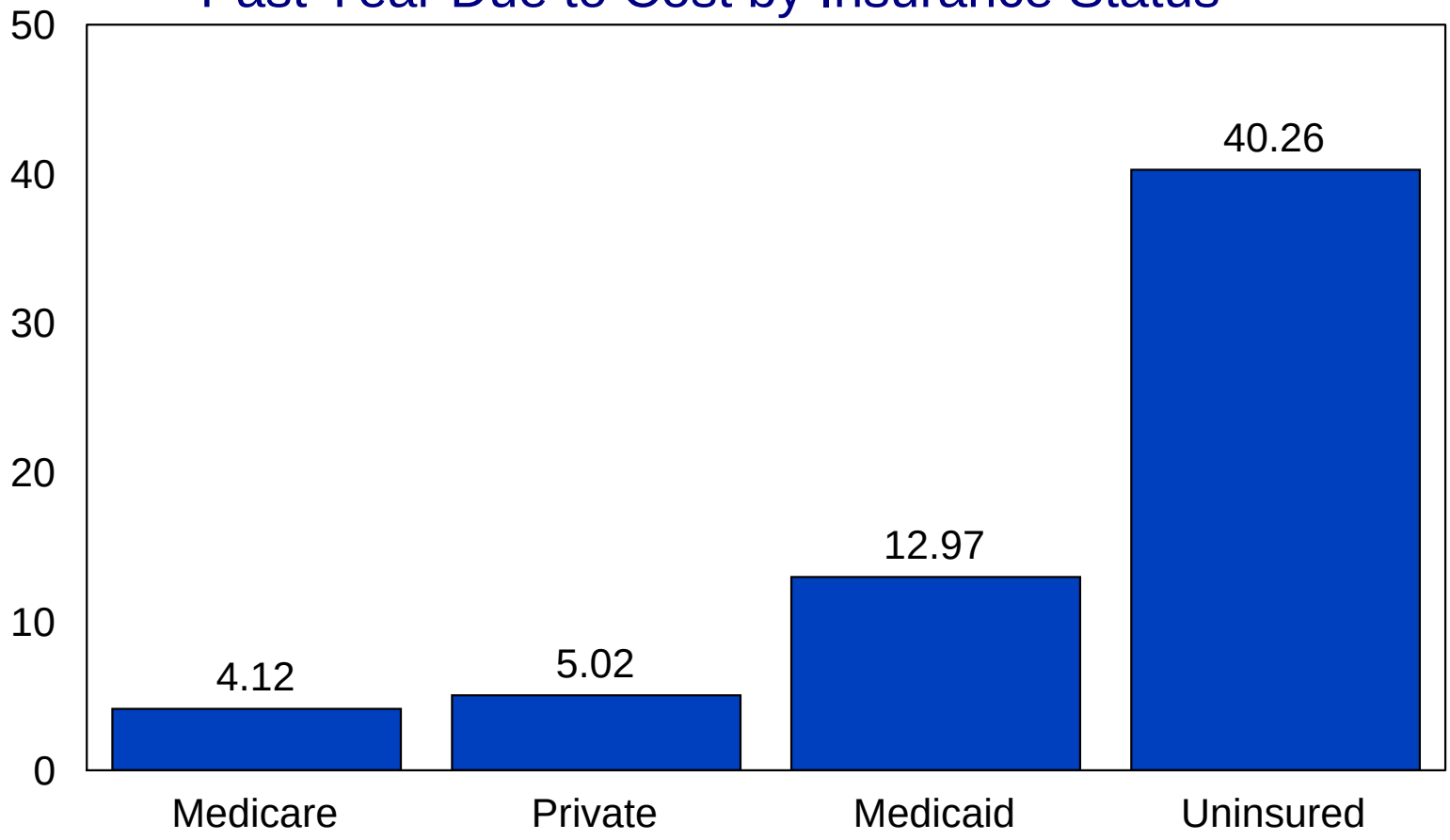
Percent of Rhode Islanders who did not see a Doctor in the past year due to Cost by Insurance Status

Was there a time during the past 12months when you needed to see a doctor but could not because of cost?

	YES		NO	
	Count	Percent	Count	Percent
Type of Insurance				
Medicare	8,266	4.76	164,847	94.94
Private	24,207	5.02	457,070	94.85
Medicaid	2,300	12.97	15,363	86.63
Uninsured	25,273	40.26	37,325	59.47

Source: Medicaid Data Archive
Behavioral Risk Factor Surveillance System (BRFSS)
3 year total 1996-98

Figure 9
Percent of Rhode Islanders Who Did Not See a Doctor in the Past Year Due to Cost by Insurance Status



Medicaid Data Archive
Behavioral Risk Factor Surveillance System, RI Department of Health
3 year average 1996-98

2. Asthma Hospitalizations

Asthma is a health condition for which timely and effective primary care and education can reduce the risk of hospitalization. The hospital discharge data set allows for the presentation of 5 years of data on asthma hospitalizations by age. The age-specific asthma hospitalization rates with their associated 95% confidence intervals provide a means to monitor change through time and identify significant differences among groups.

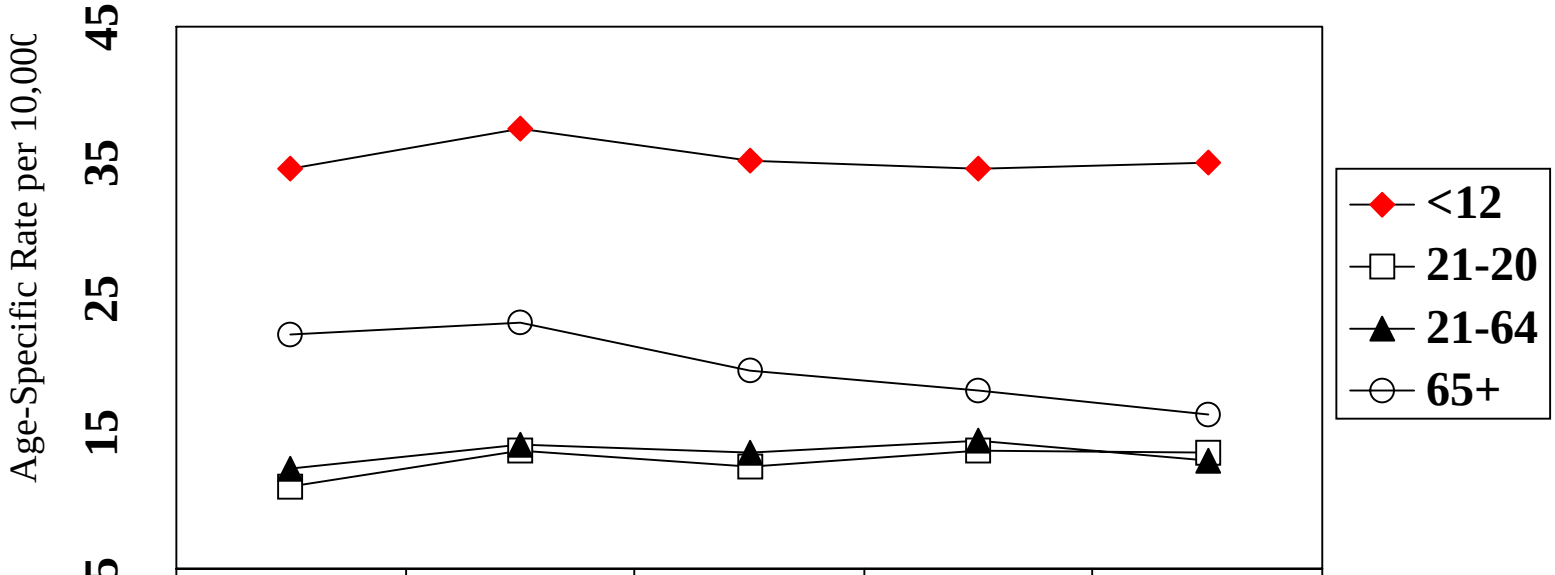
With the exception of the 65 and over age group, there has been little change in the rates of preventable asthma hospitalizations within age groups. The rate of asthma preventable hospitalization for the 65 and over age group is decreasing.

The rates for the under age 12 group are the highest of all age groups. The difference between the rates for the under age 12 group and each of the other age groups is statistically significant.

Table 2 Asthma Preventable Hospitalizations by Age for Rhode Islanders 1992-1996				
	Year	Count	Age-Specific Rate per 10,000	95% of the time the true rate will fall in this range
< Age 12	1992	536	34.49	(31.57, 37.40)
	1993	583	37.51	(34.47, 40.55)
	1994	546	35.13	(32.19, 38.07)
	1995	536	34.49	(31.57, 37.40)
	1996	544	35.00	(32.07, 37.94)
Age 12-20	1992	139	11.10	(9.26, 12.95)
	1993	172	13.74	(11.69, 15.79)
	1994	157	12.54	(10.58, 14.50)
	1995	171	13.66	(11.61, 15.70)
	1996	169	13.50	(11.46, 15.53)
Age 21-64	1992	707	12.35	(11.44, 13.26)
	1993	804	14.05	(13.08, 15.02)
	1994	775	13.54	(12.59, 14.49)
	1995	821	14.35	(13.37, 15.33)
	1996	744	13.00	(12.07, 13.93)
Age 65+	1992	336	22.32	(19.93, 24.70)
	1993	349	23.18	(20.75, 25.61)
	1994	295	19.60	(17.36, 21.83)
	1995	274	18.20	(16.05, 20.35)
	1996	246	16.34	(14.30, 18.38)

Source: Medicaid Data Archive, Hospital Discharge Data Sets (1992-96), RI Department of Health
Note: The 1990 U.S. Census population counts were used for all rate calculations for all years.

Figure 10
Rate of Asthma Hospitalizations for Rhode Islanders by Age 1992-1996



	1992	1993	1994	1995	1996
<12	34.5	37.5	35.1	34.5	35
21-20	11.1	13.7	12.5	13.7	13.5
21-64	12.4	14.1	13.5	14.4	13
65+	22.3	23.2	19.6	18.2	16.3

Medicaid Data Archive – Hospital Discharge Data Set

Appendix 1

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APPENDIX 2

HEALTH INDICATORS FOR ADOLESCENTS

HEALTH INDICATORS FOR ADOLESCENTS

Figure 1: Recommendations from Policy Studies

Figure 2: Database Availability

Developed by:
Evaluation Studies Workgroup
Division of Health Care Quality, Financing, and Purchasing
RI Department of Human Services

Developed for: Center for Health Care Strategies Project - "Development of a Health Indicator System for Rhode Islanders on Medicaid"
May 10, 1999

FIGURE 1: RECOMMENDED HEALTH INDICATORS FOR ADOLESCENTS											
	Foundation &Professional groups - Policy Recommendations				Performance measures/Quality Assurance for health plans					DHHS -needs assessments	
INDICATOR	AMA Y2000	RWJ	MoHIS	Kids Count	NLHI	CON QUEST	HEDIS	HCQUIS	FACCT	HRSA	OASPE
Primary Care Utilization/Prevention											
Physical exams, check-ups**		x					x	x		x	
Dental visits**	x	x					x	x			x
Family planning visits	x	x					x				x
Mental health visits/readmits**			x				x	x			
Immunization (HepB)**		x					x				x
Exercise/diet/weight	x										x
Risk Taking											
Teen pregnancy (2nd time mothers)**	x		x	x						x	
Sexually Transmitted Diseases	x		x					x		x	
AIDS/HIV					x			x		x	
Sexual Activity	x									x	
Tobacco use**	x	x					x	x	x	x	x
Alcohol use**	x	x			x		x	x	x	x	x
Drug use**	x	x	x		x	x	x	x	x	x	x
Unintentional Injury	x								x		
Motor Vehicle Accidents								x			x
Violence/Homicide	x		x	x						x	x
School drop-out				x						x	x
Chronic Conditions											
Depression/Suicide**	x		x	x	x	x			x	x	x
Diabetes					x	x	x	x	x		
Asthma			x		x	x	x	x			

Reports reviewed:

Policy Recommendations:

AMA - Healthy Youth 2000, 1991 - American Medical Association adopted CDCs Year 2000 health objectives aimed at adolescents
RWJ - Access to Health Care: Key Indicators for Policy 1993 & Substance Abuse The Nation's #1 Health Problem - utilization and outcome measures
MoHIS - The Missouri Health Indicator Set, 1996 - consensus group developed a set of health quality measures for the Robert Wood Johnson Foundation
Kids Count - Kids Count Data Book, 1998 - developed benchmarks to create state profiles and track the health status of children

Performance Measures:

NLHI - National Library of Health Care Indicators, 1997 - Joint Commission on Accreditation of Health Care Organizations (JCAHCO) reviewed 225 performance measures and selected key indicators for health plans
CONQUEST - A Computerized Needs Oriented Quality Measurement Evaluation System , 1996 - combines clinical performance measures form 53 measure sets (e.g., Hedis, RAND, etc) to create condition database of 52 clinical conditions/diagnoses -developed by Harvard School of Public Health for AHCPR

HCQUIS - A Health Care Quality Improvement System for Medicaid Managed Care , 1993 - performance measures developed for states by HCFA
HEDIS - Health Plan Employer Data and Information Set (HEDIS) 3.0, 1997 - performance measures developed by National Committee for Quality Assurance (NCQA) with HCFA & APWA
FACCT - Foundation for Accountability (FACCT) Performance Measures, 1996 - performance measures developed by FACCT(Jackson Hole Group)

Needs Assessment:

HRSA - America's Adolescents: Are they Healthy?, 1998 - Needs assessment conducted by Institute for Health Policy Studies at University of CA, San Francisco. An overview of adolescent health with available, reliable data
OASPE - Trends in the Well-Being of America's Children and Youth, 1998 - Needs assessment conducted by Brett Brown at Child Trends for Office of the Assistant Secretary for Planning and Evaluation.
Reliable estimates on 80 indicators of child well-being. Indicators selected from 20 national presentations.
Selection criteria include, availability, national and state comparison, ongoing collection, timeliness

** = Medicaid Program selected as priority

FIGURE 2: RECOMMENDED HEALTH INDICATORS FOR RI ADOLESCENTS BY AVAILABLE STATE DATA SOURCE

INDICATOR	Vital Statistics - Birth	Hospital Discharge	Encounter/ MMIS		
Primary Care Utilization/Prevention					
Physical exams, check-ups**			x		
Dental visits**		x	x		
Family planning visits			x		
Mental health visits/readmits**		x	x		
Immunization**(HepB)			x		
Exercise/diet/weight					
Risk Taking					
Teen pregnancy (2nd time mothers)**	x				
Sexually Transmitted Diseases		x			
AIDS/HIV		x	x		
Sexual Activity					
Tobacco use**					
Alcohol use**					
Drug use**					
Unintentional Injury		x			
Motor Vehicle Accidents		x	x		
Violence/Homicide		x	x		
School drop-out			x		
Chronic Conditions					
Depression/Suicide**		x	x		
Diabetes		x	x		
Asthma		x	x		

** = Medicaid program selected as priority

APPENDIX 3

HEALTH INDICATORS FOR HEALTHY ADULTS

HEALTH INDICATORS FOR HEALTHY ADULTS

Figure 1: Recommendations from Policy Studies

Figure 2: Database Availability

Developed by:
Evaluation Studies Workgroup
Division of Health Care Quality, Financing and Purchasing
RI Department of Human Services

Developed for:
Center for Health Care Strategies Project
Development of a Health Indicator System

for Rhode Islanders on Medicaid"
May 10, 1999

FIGURE 1: RECOMMENDED HEALTH INDICATORS FOR HEALTHY ADULTS								
INDICATOR	RI Year 2000	RWJ	IOM	HCQUIS	HEDIS	FACCT	CON-QUEST	MoHIS
Prevention:								
CVD Screening (cholesterol)	x			x	x			x
Breast Cancer Screening (mammography)	x		x				x	
Cervical Cancer Screening (pap smears)	x	x	x		x	x	x	x
Colorectal Cancer Screening		x					x	x
Diabetic Retinal Exams					x	x		x
Influenza/pneumonia vaccination *		x		x	x	x		x
Tobacco use	x	x		x		x		
Alcohol use	x	x		x		x		
Drug use	x	x		x			x	x
Screening for Chronic Disease								
Depression/Suicide	x			x	x	x	x	x
Mental Disability	x			x	x		x	x
Chronic disease follow-up			x			x		
Hypertension	x					x	x	
Tuberculosis	x			x				
Breast cancer - stage of dx	x					x	x	x
Cervical cancer - stage of dx	x						x	x
Colorectal cancer - stage of dx							x	x
HIV	x						x	

INDICATOR	RI Year 2000	RWJ	IOM	HCQUIS	HEDIS	FACCT	CON-QUEST	MOHIS
Hospitalizations for ACS Conditions:			x		x			
Pneumonia		x	x		x		x	
Cellulitis		x	x		x			
UTI		x	x		x			
Dehydration		x	x		x			
Gastroenteritis/Dehydration		x	x		x			
Asthma		x	x	x	x	x	x	x
Chronic Obstructive Pulmonary Dis.		x	x	x	x		x	
Congestive Heart Failure		x	x	x	x		x	x
Angina		x	x	x	x			
Diabetes		x	x		x	x	x	
Other Hospitalizations:								
Myocardial infraction				x			x	x
Hysterectomies				x				x
Hip fracture				x				x

References:

RI Year 2000 - Year 2000 health objectives developed by the Department of Health with community agency and consumer input

RWJ - utilization and outcome measures from publication- Access to Health Care: Key Indicators for Policy 1993 or Substance Abuse: Key Indicators for Policy, 1993

IOM - utilization and outcome measures from book - Access to Health Care in America, National Academy of Sciences, 1993

HCQUIS - performance measures developed by DHHS, HCFA, 1993

HEDIS - performance measures developed by National Committee for Quality Assurance in conjunction with HCFA & APWA, 1997

FACCT - performance measures developed by Foundation for Accountability (Jackson Hole Group)

CONQUEST - A Computerized Needs Oriented Quality Measurement Education System developed by Harvard School of Public Health for AHCPR, 1996

MoHIS - developed by Missouri Health Systems Partnership for the Robert Wood Johnson Foundation, 1996

FIGURE 2: RECOMMENDED HEALTH INDICATORS FOR HEALTHY ADULTS BY AVAILABLE DATABASES						
INDICATOR	Death File	Hospital Discharge	BRFSS	RIHIS	Special Survey	MMIS
Prevention:						
CVD Screening (cholesterol)			x			x
Breast Cancer Screening (mammography)			x			x
Cervical Cancer Screening (pap smears)			x			x
Colorectal Cancer Screening						x
Diabetic Retinal Exams			x			x
Influenza/pneumonia vaccination			x			x
Dental				x		x
Tobacco use			x	x		
Alcohol use			x	x		
Drug use			x	x		
Chronic Disease:						
Depression/Suicide	x					
Mental Disability						
Functional Status			x	x		
Chronic disease follow-up						
Hypertension			x	x		
Tuberculosis						
Breast cancer - stage of dx						
Cervical cancer - stage of dx						
Colorectal cancer - stage of dx						
HIV	x		x			

INDICATOR	Death File	Hospital Discharge	BRFSS	RIHIS	Special Survey	MMIS
Hospitalizations for ACS Conditions:						
Pneumonia		x				
Cellulitis		x				
UTI		x				
Dehydration		x				
Gastroenteritis/Dehydration		x				
Asthma		x				
Chronic Obstructive Pulmonary		x				
Congestive Heart Failure		x				
Angina		x				
Diabetes		x				
Other Hospitalizations:						
Myocardial infraction		x				
Hysterectomies		x				
Hip fracture		x				

APPENDIX 4

HEALTH INDICATORS FOR CHILDREN WITH DISABILITIES

HEALTH INDICATORS

FOR CHILDREN WITH DISABILITIES

Figure 1: Recommendations from Policy Studies

Figure 2: Database Availability

Developed by:
Evaluation Studies Workgroup
Division of Health Care Quality, Financing, and Purchasing
RI Department of Human Services

Developed for: Center for Health Care Strategies Project - "Development of a Health Indicator System for Rhode Islanders on Medicaid"
January 27, 2000

FIGURE 1: RECOMMENDED HEALTH INDICATORS FOR CHILDREN WITH DISABILITIES

	Accreditation groups/ Consensus panels		Policy/government groups		Published in journals			
	FACCT/ NCQA	NACHRI	TitleV - MCHB	Johns Hopkins	Kuhlthau	Newa-check	Powe	Pantel
STRUCTURE								
Easy physical access to facility				X		X		
Adequate number of pediatric specialists **			X	X	X	X		
Pediatricians have clinical knowledge of disability				X		X		
Access to care weekends and nights *				X		X		
Support services available -(i.e., transportation, homecare, respite) **				X		X		
Written linkages in place - state health, education, social service agencies		X		X	X			
Quality of care protocols in place		X			X			
Grievance and appeals process in place (esp for medical equipment)				X	X	X		
Parents on advisory group			X		X			
PROCESS								
Utililization:		X						
Preventive visits (i.e. well child)	X			X	X		X	X
Acute visits	X			X				
Dental				X		X		
Emergency *	X						X	
Mental health				X	X			
Pharmacy/RX	X			X				
Hospital Readmits *							X	

	FACCT/ NCQA	NACHRI	TitleV - MCHB	Johns Hopkins	Kuhlthau	Newa-check	Powe	Pantel
Access (how hard is it to get):								
Specialty care referral	X			X		X		
Specialty care appointments **	X			X				
Durable medical equipment/assistive tech **	X			X		X		
Physical, speech, occupational therapy	X			X		X		
Mental health counseling *	X			X	X			
Respite care *				X		X		
Up-to-date on Immunization		X			X	X		X
Received appropriate preventive screening (e.g.,lead,anemia)		X	X		X			
Length of time with PCP			X	X				
Family received written information on condition	X	X						
Family knowledge of child's condition	X			X		X		
Communication level:								
Doctors and other providers coordinate care plan with schools **	X	X		X	X			
Primary care provider & specialty provider coordinate care plan	X			X	X	X		
OUTCOME								
Screening Q for disability	X							
Functional status **		X			X	X		
Emotional functioning *						X		X
Social functioning *						X		X
Global health status		X				X		
School performance **						X		X
School days missed						X		
Number of bed days						X		
Total annual $ spent on child						X	X	

	FACCT/ NCQA	NACHRI	TitleV - MCHB	Johns Hopkins	Kuhlthau	Newa-check	Powe	Pantel
Care appropriate for developmental level of child		X		X				
Satisfaction with doctor/provider:	X			X		X		
Support and understanding	X			X		X		
Communication and listening skills	X			X		X		
Knowledge of condition	X					X		
Satisfaction with office/other staff:	X			X		X		
Respect for child and family	X			X				

References:

FACCT/NCQA - Foundation for Accountability, Bethell C, Read D, Hochheimer J, Pediatric Living with Illness Module (LWIM), FACCT/NCQA, Draft October 1999.

NACHRI - National Association of Children's Hospitals and Related Institutions (NACHRI). Pediatric Excellence in Health Delivery Systems, "Measures of Excellence - Chronic Care". VA: NACHRI, June 1996.

MCHB - Maternal & Child Health Bureau (MCHB)/Title V, MCH Performance Measures

John Hopkins - Johns Hopkins National Policy Center for Children with Special Health Care Needs, Ireys H, Minkovitz C, Anderson G, Grason H, Connallon J. "Specific Measures of Quality Related to Health Services for Special Health Care Needs" from Quality Measurements for Children with Special Health Care Needs, September 1999.

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Pantel R, Lewis C, "Measuring the Impact of Medical Care on Children." Journal Chronic Disease 40: 995-1085, 1987

* program priority
** highest program priority

FIGURE 2: RECOMMENDED HEALTH INDICATORS FOR CHILDREN WITH DISABILITIES DATABASE AVAILABILITY

	Medicaid Management Information System (MMIS)	Children with Disabilities Needs Assesssment	CEDARR Intake
Easy physical access to facility			
Adequate number of pediatric specialists			
Pediatricians have clinical knowledge of disability			
Access to care weekends and nights			
Support services available -(i.e., transportation, homecare, respite		X	
Written linkages in place - state health, education, social service agencies			
Quality of care protocols in place			
Grievance and appeals process in place (esp for medical equipment)			
Parents on advisory group			
Utililization:			
Preventive visits (i.e. well child)	X	X	
Acute visits	X	X	
Dental	X	X	
Emergency	X	X	
Mental health	X		
Pharmacy/RX	X		
Hospital Readmits	X		
Access (how hard is it to get):			
Specialty care referral		X	
Specialty care appointments	X	X	
Durable medical equipment/assistive tech	X	X	X

	Medicaid Management Information System (MMIS)	Children with Disabilities Needs Assessment	CEDARR Intake
Physical, speech, occupational therapy	X	X	
Mental health counseling	X		
Respite care	X	X	
Up-to-date on Immunization			
Received appropriate preventive screening (e.g.,lead,anemia)			
Length of time with PCP	X		
Family received written information on condition			X
Family knowledge of child's condition		X	
Communication level:			
Doctors and other providers coordinate care plan with schools			
Primary care provider and specialty provider coordinate care plan			
Screening Q for disability			
Functional status		X	X
Global health status			
School performance			
School days missed		X	
Number of bed days		X	
Total annual $ spent on child	X		
Care appropriate for developmental level of child			
Satisfaction with doctor/provider:			
Support and understanding		X	
Communication and listening skills		X	
Knowledge of condition		X	
Satisfaction with office/other staff:			
Respect for child and family		X	

APPENDIX 5

HEALTH INDICATORS FOR ADULTS WITH DISABILITIES

HEALTH INDICATORS FOR ADULTS WITH DISABILITIES

Figure 1: Recommendations from Policy Studies

Figure 2: Database Availability

Developed by:
Evaluation Studies Workgroup
Division of Health Care Quality, Financing and Purchasing
RI Department of Human Services

Developed for:
Center for Health Care Strategies Project
"Development of a Health Indicator System for Rhode Islanders on Medicaid"
February 29, 2000

FIGURE 1: RECOMMENDED HEALTH INDICATORS FOR ADULTS WITH DISABILITIES

INDICATOR	Draft-CDC 2010	RWJF IHA	ASPE Soafer	PACE	FACCT ONE	CAHPS	RWJ PMG	NHLI	Quismic	CHCS Measures
STRUCTURE:										
Assisted Living Facilities	X	X								
Adult Foster Care	X	X								
Specialists			X			X				
DME			X			X				
"System" Capacity (community based services, case managers & ombudsman)		X	X							
Linkages (acute & chronic)			X							
PROCESS:										
Nursing Home (Stays & Days)	X	X		X						
Hospital Stays (Stays & Days)		X		X		X		X		
Emergency Department Visits		X	X					X		
Skilled Home Health (nursing)	X	X	X			X				
Unskilled Home Health (home health aid)	X			X		X				
Rehab Services (PT, OT, ST)		X				X				
Adult Day Care	X									
Respite Services			X							
Readmits (psych & mental) **		X	X	X			X	X		X
ACS Hospitalizations **			X				X			X
Mental health outpatient			X	X						
Chronic Follow-up Care (diabetes, depression, asthma, aids)		X								X
Functional Assessment	X		X							

INDICATOR	Draft-CDC 2010	RWJF IHA	ASPE Soafer	PACE	FACCT ONE	CAHPS	RWJ PMG	NHLI	Quismic	CHCS Measures
Depression Screen	X		X							X
Substance Abuse Screen	X		X							X
OUTCOME:										
Functional Status **	X	X	X		X	X	X	X	X	X
Depression **	X	X						X		
Unmet Need for Care		X				X				
Pain/Symptoms **			X		X			X		X
Satisfaction (Access in emergency ** MD Knowledge, etc.)		X	X	X	X	X	X	X	X	X
Patient Knowledge of Condition					X				X	
Patient Involvement in Care					X	X			X	
Social Functioning (work & family)		X						X		X
Family Satisfaction		X								

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CHCS: Center for Health Care Strategies, Performance Measures Workgroup Report, 2000

**** Program priorities**

FIGURE 2: RECOMMENDED HEALTH INDICATORS FOR ADULTS WITH DISABILITIES - DATABASE AVAILABILITY

INDICATOR	MMIS - Claims	Hospital Discharge	Needs assessment Survey		
STRUCTURE:					
Assisted Living Facilities	X				
Adult Foster Care					
Specialists	X				
DME					
"System" Capacity (community based services, case managers & ombudsman)					
Linkages (acute & chronic)			X		
PROCESS:					
Nursing Home (Stays & Days)	X				
Hospital (Stays & Days)	X				
Emergency Department Visits	X		X		
Skilled Home Health					
Unskilled Home Health					
Rehab Services (PT, OT, ST)	X				
Adult Day Care					
Respite Services					
Readmits (7,14,30 days) **	X				
ACS Hospitalizations **	X	X			
Psych hospital/Mental health					

INDICATOR	MMIS - Claims	Hospital Discharge	Needs Assessment Survey		
Chronic Follow-up Care			X		
Primary Care Doctor Visits	X		X		
Functional Assessment			X		
Depression Screen			X		
Substance Abuse Screen					
OUTCOME:					
Functional Status **			X		
Depression **			X		
Unmet Need for Care	X		X		
Average Costs	X				
Pain/Symptoms **			X		
Satisfaction (Access in emergency ** MD Knowledge, etc.)			X		
Patient Knowledge of Condition					
Patient Involvement in Care					
Work					
Social Activity					
Family Satisfaction					

** program priorities

APPENDIX 6

STATE AGENCY STAKEHOLDER PARTICIPANTS

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APPENDIX 7

DESCRIPTION OF DATA SETS SELECTED FOR RHODE ISLAND MEDICAID DATA ARCHIVE

1. HOSPITAL DISCHARGE DATA SET

Purpose: The Rhode Island Hospital Discharge Data Set is a legally mandated data collection activity. Hospital licensure regulations require all acute care hospitals to report discharge data for all inpatients. The hospital discharge data housed in the Medicaid Data Archive are for Ambulatory Care Sensitive Conditions (ACS) only. A copy of the complete statewide data set is stored electronically in the Office of Health Statistics at the Department of Health.

This data set allows for an analysis of changes in hospital utilization by diagnoses. Especially important is the tracking of ACS conditions. ACS conditions are those for which timely and effective primary care reduces the risk of hospitalization.

Source: Rhode Island Department of Health, Office of Health Statistics

Characteristics

Method of Data Collection: Rhode Island Hospitals are required to provide information on all inpatients, regardless of residency, who are admitted into Rhode Island acute care hospitals. Data are abstracted from patients' medical records. This data collection activity is ongoing. Data are released yearly for analysis and reporting between 6 to 9 months after the last day of the hospital's fiscal year
(10/1- 9/30).

Population: This data set contains data for all persons admitted for overnight stays to acute care hospitals in Rhode Island. Again, the hospital discharge data set housed in the Medicaid Data Archive contains only admission data for ACS conditions. The data contain information by age, sex, race/Hispanic origin, insurance status and diagnoses.

Years Available in Medicaid Data Archive: 1992 - 1997

Selected Health Indicators Under Review:

Ambulatory Care Sensitive conditions by type of insurance:

Pneumonia	Diabetes
Cellulitis	Angina
UTI	Asthma
Dehydration	Gastroenteritis/Dehydration
Congestive heart failure	Pelvic Inflammatory Disease
Chronic obstructive pulmonary	

Length of stay and cost data will also be tracked for ACS conditions

2. VITAL STATISTICS BIRTH FILE

Purpose: The Division of Vital Statistics in the Department of Health has a legal mandate to certify the occurrence of all births. Through cooperative agreements among states, data for births to Rhode Island residents which occur out-of-state are also recorded in the data set. Among other topics, these data allow for the analysis of changes in prenatal care utilization and birth outcomes over time.

Source: Rhode Island Department of Health, Office of Vital Records

Characteristics

Method of Data Collection: There is an automatic vital statistics reporting system in place at the maternity hospitals in Rhode Islands. Home births are reported by parents.

Population: This data set includes information for all births to Rhode Islanders by mother's age, race/Hispanic origin, education, marital status, and residence. The data set also includes information on practice setting, prenatal care utilization, birth outcomes, and insurance status.

Years Available in Medicaid Data Archive: 1993 - 1998

Selected Health Indicators:

By type of insurance:

Inter-birth interval
Time of entry into prenatal care
Number of prenatal care visits
Adequacy of prenatal care
Birthweight
Gestational Age
Maternal smoking
Teen pregnancy (2^{nd} time mothers)

3. MINIMUM DATA SET (MDS), NURSING HOME DATA

Purpose: The Minimum data Set, Nursing Home Data provides comprehensive data on nursing home residents' strengths,, weaknesses and problems. These data are collected as a means of evaluating the appropriateness of care in nursing facilities. The data set provides an in-depth assessment of 18 conditions that affect the functional well being of nursing home residents including information on falls, urinary incontinence, cognition, and use of restraints.

Source: The Health Care Financing Administration

Characteristics

Method of Data Collection: This data set is a uniform resident assessment system. In 1988 HCFA contracted with the Research Triangle Institute, the Hebrew Rehabilitation Center for the Aged, Brown University, and the University of Michigan to develop and evaluate a uniform resident assessment system. In the collection of the data, the MDS assessment approach relies on the input of multiple disciplines and multiple individuals interacting with each resident throughout the course of the day and night. As of 1994, 10 states have computerized the collection of MDS data.

Population: All residents of nursing facilities. Data are collected for these persons by age, sex, race/ethnicity, insurance status, education, occupation and for 18 conditions affecting nursing home residents' well being. Each resident is assessed periodically and the time and reason for each assessment is recorded.

Years Available: To be determined

Selected Health Indicators Under Review:

By type of insurance:

Use of restraints
Falls
Pressure ulcers
Hospitalizations for ACS conditions
Use of Catheters
Number of primary care visits
Flu/Pneumonia Vaccination
Physical Therapy
Report of pain/depression

4. BEHAVIORAL RISK FACTOR SURVEILLANCE SURVEY (BRFSS)

Purpose: The Centers for Disease Control and Prevention fund states to conduct surveys on behavioral health risks. The information collected in the survey examine those personal behaviors that can be viewed as the 'real causes of death.'

Source: Rhode Island Department of Health, Office of Health Statistics

Characteristics

Method of Data Collection: The Behavioral Risk Factor Surveillance Survey is a telephone survey of Rhode Islanders conducted on a monthly basis. An annual sample of 1,800 Rhode Island adults is randomly selected to participate in the survey. Data are obtained on the residents of these households and the data are representative of the adult population of Rhode Island. This survey is conducted by a professional survey organization under the auspices of the Rhode Island Department of Health.

Population: Data are collected for persons age 18 and over. Among other details, the data are provided by age, sex, race/Hispanic origin, and insurance status.

Years Available in Medicaid Data Archive: CY1996 - 1998

Selected Health Indicators Under Review:

By type of insurance:

Breast Cancer Screening
Cervical Cancer Screening
Cholesterol Screening (CVD)
Diabetic Retinal Exams
Influenza/Pneumonia Vaccination
Tobacco Use
Alcohol Use
Drug Use
Functional Status
Hypertension
HIV

5. RHODE ISLAND HEALTH INTERVIEW SURVEY

Purpose: The Rhode Island Health Interview Survey collects information from Rhode Islanders about their health status, health behaviors, health insurance coverage, access to health care and other related health topics.

Source: Rhode Island Department of Health, Office of Health Statistics

Characteristics

Method of Data Collection: The Health Interview Survey is a telephone survey of Rhode Islanders conducted approximately every five years. This survey is conducted by a professional survey organization. A sample of 2,300 to 2,500 households are randomly selected to participate in the survey and the data obtained on the residents of these households are representative of the overall population of Rhode Island.

Population: The data set provides health information for all Rhode Islanders. The data provide detail on age, sex, race/Hispanic origin, education, income and insurance status.

Years Available in Medicaid Data Archive: 1990 and 1996

Selected Health Indicators Under Review:

By type of insurance:

Mammography Screening
Dental
Tobacco Use
Alcohol Use
Drug Use
Hypertension
Disability Status including:
Asthma
Emphysema/Chronic Bronchitis
Cerebral Palsy
Arthritis
Rheumatism
Alzheimer's Disease
Incontinence

6. INFANT HEALTH SURVEY

Purpose: The Infant Health Survey was a pre-/post-evaluation study of the impact of RIte Care, Rhode Island's Medicaid managed care program for Medicaid families and uninsured pregnant women and children. Among the topics covered, the survey collected information on entry into primary care, number of primary and acute care visits, immunizations, barriers to care and satisfaction with care in the infant's first year of birth.

This is a special focused study of 600 inner city mothers of one year olds. It provides a comprehensive view of health care needs, utilization, barriers to health care, inappropriate use of health services and quality of care for this high risk population.

Source: Rhode Island Department of Human Services, RIte Care Program

Characteristics

Method of Data Collection: The sample for this evaluation study were two inner city birth cohorts. The first, 1993 Cohort (pre-RIte Care), included resident births for a selection of Providence inner city census tracts that occurred from 3/1/93 to 7/30/93. The second, 1995 Cohort (post-RIte Care), included resident births for the same Providence inner city census tracts that occurred from 3/1/95 to 7/30/95. Face-to-face interviews were conducted with mothers when the infants were one year old. The survey was conducted by MCH Evaluation, Inc.

Population: The population detailed in this survey is inner city low income mothers and infants. The data collected provide information on access to primary and preventive health care for this high risk population.

Years Available in Medicaid Data Archive: 1993 and 1995

Selected Health Indicators

Entry into pediatric care
Adequacy of pediatric care - number of preventive and acute visits
Up- to-date on Immunization
Up-to date on pediatric screening - lead, anemia
Emergency and Hospital utilization
Satisfaction with care
Barriers to care

7. CHILDREN WITH DISABILITY SURVEY

Purpose: The purpose of this needs assessment survey was to collect information to provide a fuller understanding of the health care needs of Rhode Island children and adolescents with disabilities on Medicaid. The survey was funded by the Rhode Island Department of Human Services and the Rhode Island Department of Health.

Source: Rhode Island Department of Human Services, RIte Care Program

Characteristics

Method of Data Collection: The Children with Disability Survey collected information from a statewide random sample of 257 caregivers of children and adolescents, ages 1 – 21, with disabilities on fee-for-service Medical Assistance. Interviews with caregivers were conducted by telephone or in-person from October of 1997 through December of 1997. The survey was conducted by MCH Evaluation, Inc.

Population: The data collected are representative of all Rhode Island children and adolescents with disabilities on Medicaid. Among other topics, the data provide detail by age, sex, household income, disability status, health status and functional limitations.

Years Available in MedicaidData Archive: 1997

Selected Health Indicators:

For children and adolescents with disabilities on fee-for-service Medical Assistance:

Primary Care Utilization
Specialty Care Utilization
Emergency Department Utilization
Hospital Utilization
Satisfaction with Care
Barriers to Care
Unmet Health Needs

8. MEDICAID MANAGEMENT INFORMATION SYSTEM (MMIS)

Purpose: The MMIS is a computerized transaction system that records data for persons enrolled in Medicaid programs and for all claims submitted to the Medicaid program. Among other items, the database records claim information on hospitalizations, emergency room visits, home health visits by diagnoses, services provided and costs.

Source: Rhode Island Department of Human Services

Characteristics

Method of Data Collection: The MMIS system is a computerized transaction system recording both the registration of eligible persons and all claims for payment made to the Medicaid program. This database is overseen by the Rhode Island Department of Human Services through a contract with Electronic Data Systems (EDS).

Population: All persons who meet specific eligibility criteria for Medicaid enrollment. The Medicaid enrolled population is profiled by age, sex, and race/Hispanic origin. Submitted claims include information on setting of service provision, diagnoses, services provided and costs.

Years Available in Medicaid Data Archive : 1998

Selected Health Indicators Under Review:

For the Medicaid population:

For Adults:

Breast Cancer Screening	Cervical Cancer Screening
Colorectal Cancer Screening	Cholesterol Screening (CVD)
Diabetic Retinal Exams	Dental
Influenza/pneumonia vaccination	Emergency Dept and Hospital stays

For Adolescents:

Physical exams	Dental
Family planning visits	Mental health visits/readmits
Immunization (Hepatitis B)	AIDS/HIV